




ORIGINAL ARTICLE

Living with support: Experiences of people with mild intellectual disability

Sanne A. H. Giesbers^{1,2}  | Lex Hendriks³ | Andrew Jahoda⁴  |
Richard P. Hastings^{5,6} | Petri J. C. M. Embregts¹ 

¹Tranzo, Tilburg School of Social and Behavioral Sciences, Tilburg University, Tilburg, The Netherlands

²Dichterbij Innovation and Science, Gennep, The Netherlands

³School of Pedagogical and Educational Science, Faculty of Social Sciences, Radboud University, Nijmegen, The Netherlands

⁴Psychological Medicine, University of Glasgow, Glasgow, UK

⁵Centre for Educational Development, Appraisal and Research, University of Warwick, Coventry, UK

⁶Department of Psychiatry, Centre for Developmental Psychiatry and Psychology, School of Clinical Sciences at Monash Health, Monash University, Melbourne, Vic., Australia

Correspondence

Sanne A. H. Giesbers, Tilburg University, Tilburg, The Netherlands.
Email: s.a.h.giesbers@tilburguniversity.edu

Funding information

The research was funded by service provider Dichterbij. Dichterbij has not imposed any restrictions on free access to or publication of the research data.

Abstract

Background: To enhance social inclusion of people with intellectual disability, policy is aimed at increasing informal support networks. Nevertheless, staff continue to play a vital role in their support networks.

Method: Six individuals with mild intellectual disability, living in community-based settings, were interviewed following a semi-structured format. In-depth accounts of participants' support experiences were established using Interpretative Phenomenological Analysis.

Results: Three main themes were identified: relationships with staff placed within a personal history, relationships with staff within an organisational context, and staff support and interviewees' place in the world.

Conclusions: Relationships with staff were often one of the closest and most significant social relationships participants had. As living in the community had not necessarily led to meaningful inclusion for participants, the findings point at the important role of staff in supporting and facilitating friendships and close relationships of people with intellectual disability.

1 | INTRODUCTION

There has been increasing recognition that people with intellectual disability are full citizens with the same rights as non-disabled persons and that they should be supported in making their own decisions and participating equally in society (Devi, 2014). Participation and social inclusion have dominated the policy discourse within western society (e.g., Hewitt, Nord, Bogenschutz, & Reinke, 2013). For example, in the Netherlands, rights for people with disabilities have

been officially acknowledged by the relatively recent (2016) ratification of the United Nations' Convention on the Rights of Persons with Disabilities (UNCRDP; United Nations, 2006). The perspective of people with intellectual disability themselves has become a central aspect in support provision. They should determine, as far as possible, their own support needs and should have a say in how this support is provided (Embregts, 2011).

To enhance participation and social inclusion, there has been an emphasis on supporting individuals to forge stronger links with

This manuscript has not been previously published and is not under consideration in the same or substantially similar form in any other (peer-reviewed) media. All authors listed have contributed sufficiently to the project to be included as authors, and all those who are qualified to be authors are listed in the author byline.

This is an open access article under the terms of the Creative Commons Attribution-NonCommercial-NoDerivs License, which permits use and distribution in any medium, provided the original work is properly cited, the use is non-commercial and no modifications or adaptations are made.

© 2018 The Authors. *Journal of Applied Research in Intellectual Disabilities* Published by John Wiley & Sons Ltd

their local community, with the aim of increasing informal networks of support and reducing the need for support from paid carers. However, research has shown that the social networks of the majority of people with intellectual disability are relatively small (Lippold & Burns, 2009; Van Asselt-Goverts, Embregts, & Hendriks, 2013). Interactions between people with intellectual disability and those in the wider community may be mainly restricted to family and staff, not only for people with intellectual disability living in residential campus-style settings but also for those living independently or receiving community-based residential support (Forrester-Jones et al., 2006; Kwekkeboom, De Boer, Van Campen, & Dorrestein, 2006; Robertson et al., 2001; Van Asselt-Goverts, Embregts, & Hendriks, 2015; Verdonshot, De Witte, Reichrat, Buntinx, & Curfs, 2009). For example, Van Asselt-Goverts et al. (2013) found that around a quarter of the social networks of participants with mild intellectual disability consisted of professionals (e.g., support staff). These professionals were highly valued by people with mild intellectual disability, who relied on them for emotional and instrumental support. Thus, professionals continue to play a vital role in the lives of people with intellectual disability. Therefore, it is important to gain insight into how they perceive the support they receive from professionals or staff (McDonald, Kidney, & Patka, 2013).

Several researchers have examined how people with intellectual disability and additional psychological problems perceive the support they receive from specialist mental health services, forensic services for people with intellectual disability and mainstream mental health services (Clarkson, Murphy, Coldwell, & Dawson, 2009; Donner, Mutter, & Scior, 2010; Griffith, Hutchinson, & Hastings, 2013; Longo & Scior, 2004; Murphy, Estien, & Clare, 1996; Stenfort Kroese, Rose, Heer, & O'Brien, 2013). Relationships with staff that are based on qualities such as trust, honesty, patience, a genuine interest and a caring attitude were highly appreciated. However, some individuals found staff to be unfriendly or arrogant, unavailable, immature, short tempered and reluctant to help. Others appeared acutely aware that not all staff had an interest in working with them.

Little research has addressed the perceptions of people with intellectual disability without additional psychological problems who receive support within intellectual disability services. In a study by Kwekkeboom et al. (2006), 17 individuals with mild intellectual disability talked primarily about the emotional support they received from staff. Additionally, Reuzel, Embregts, Bosman, van Nieuwenhuizen, and Jahoda (2017) explored the perceptions and expectations of regular support meetings of people with mild to borderline intellectual disability. Interviews with nine participants immediately after their support meeting showed that during the meeting, they received helpful advice from staff. They also appreciated practical support and the opportunity to tell their story. The outcomes that they listed were consistent with the goals and expectations they outlined before their meetings.

Finally, other researchers have focused on what people with intellectual disability regard as important qualities of staff. They have stressed the importance of staff's interpersonal skills. They also valued relationships with staff characterized by attentiveness, care,

availability, reliability, trust and honesty (Barelds, Van de Goor, Van Heck, & Schols, 2010; Roeden, Maaskant, & Curfs, 2011; Roeleveld, Embregts, Henriks, & Van den Bogaard, 2011). People with intellectual disability placed more of an emphasis on interpersonal skills when defining the qualities they value in staff than staff themselves or service managers, who placed the greatest emphasis on practical skills, knowledge and managing staff stress (Dodevska & Vassos, 2013; Hatton, Wigham, & Craig, 2009). Furthermore, Roeden et al. (2011) found that people with intellectual disability want to feel that their independence and autonomy are respected by staff. As far as possible, they wanted to solve their own problems. Petner-Arrey and Copeland (2014) found that people with intellectual disability considered a caring relationship to be one that promoted their autonomy. However, staff were not always attuned to their needs and wishes, often helping them with tasks they were capable of doing themselves.

Until now, studies have not provided an in-depth account of people's support experience in the context of their broader lives and social circumstances. Therefore, in the present study, we used Interpretative Phenomenological Analysis (IPA) as the qualitative method to explore what individuals with intellectual disability thought and felt with regard to their support from staff (Smith, Flowers, & Larkin, 2009). IPA is a suitable approach when one is trying to explore how individuals perceive situations they are facing (i.e., receiving support from staff within services), and how they make sense of their personal and social world. The goal of IPA is to address how individuals make sense of events or aspects of their lives which, in turn, are embedded in their broader personal histories and social contexts. Published IPA studies typically have included samples of five to ten participants (Smith, 2004). Small sample sizes allow for in-depth engagement with each individual case, and a detailed exploration of similarities and differences between participants (Smith et al., 2009). By using IPA, we aimed to develop a better understanding of the unique experiences, challenges and needs of adults with mild intellectual disability with regard to their support.

2 | METHOD

2.1 | Participants

A purposive sample of six individuals with mild intellectual disability took part in the study: four men and two women. Characteristics of participants are provided in Table 1, and pseudonyms are used throughout to protect anonymity. The mean age of participants was 27.7 years. All participants received support within a clustered care setting and had set times for one-to-one support, but they were able to ask for additional support 24 hr a day. Staff were either based in the same or an adjacent building. All participants received support under the Dutch Long-term Care Act (Wlz). Under this act, one of six care profiles is assigned to the individual, based on the person's level and type of support needs.

TABLE 1 Characteristics of participants

Variable	Participants (Pseudonyms)					
	Lynn	Kenneth	Daniel	Jill	Thomas	Brian
Gender	Female	Male	Male	Female	Male	Male
Age (years)	23	27	32	30	22	32
Living situation	Together with another person with intellectual disability	Individually	Individually	Individually	Individually	Together with another person with intellectual disability
Additional diagnose	None	None	Motor impairment	None	Epilepsy, Attention Deficit Hyperactivity Disorder	Motor impairment, Epilepsy
IQ score	61	58	54	60	58	60
Daytime occupation	4 days a week	3 days a week	5 days a week	2 days a week	5 days a week	5 days a week
Level of support	2: living with support and more intensive input	1: living with support	1: living with support	4: living with more intensive help and behavioural support	1: living with support	1: living with support
Number of support hours	12.5–15	10.5–13	10.5–13	15–18.5	10.5–13	10.5–13

2.2 | Semi-structured interview

In line with the IPA method, we used semi-structured interviews. An interview schedule with key topic areas was developed for use in the study. The interviews covered: (a) the nature of support received by the participant (i.e., when, where and by whom is the person supported), (b) the participant's experience of support and perceived support needs (i.e., views about what support is needed and what support is provided), (c) evaluation of support (i.e., how does the person view the kind of support he/she is given and how is the support delivered), (d) the nature of the person's relationship with the support person and the nature of support he/she receives (i.e., how do the person and staff get along) and (e) the meaning of living with support (i.e., how does the person experience being supported by professionals). The schedule was piloted and discussed with two experts-by-experience of having intellectual disability and receiving supports from services. Subsequently, minor changes were made before carrying out the interviews reported in this study.

2.3 | Procedure

After ethical approval was obtained from the Ethical Review Board of Tilburg University (EC-2015.33), as well as from the review boards of the participating services, participants were recruited from two services supporting people with intellectual disability in the Netherlands. Criteria for inclusion of participants were that they (a) had mild intellectual disability (IQ scores between 50 and 70), (b) were aged between 18 and 40 years and (c) had received community-based support from the service provider for at least six months. Participants were invited in consultation with key staff members of the service providers. An information letter (covering the content of the study, the financial recognition for participation

[10 euro cash] and the confidentiality of the data) was sent to participants. Interviews took place at the homes of participants.

To ensure that participants could provide informed consent, a standard procedure was followed as described by Arscott, Dagnan, and Stenfort Kroese (1998). At the start of each interview, a verbal and written overview of the research project was presented by the interviewer. The interviewer determined whether participants could recall (a) an idea of the content of the proposed interview, (b) that they would be interviewed once, (c) possible positive and adverse aspects regarding participation and (d) that they would be free to withdraw at any time. If the participant did not initially understand the research, the researcher repeated and explained these four points in simpler or alternative words until the participant was able to respond to the consent questions, indicating that they understood the key aspects of the research procedure. Following these adjustments, all participants were able to provide informed consent.

Interviews were conducted by the first author in an open and flexible manner with topics being covered according to the direction taken by the participants, aiming to initiate a dialogue with participants, while remaining open to other subjects raised by the participants themselves. At the end of the interview, participants were given the opportunity to raise additional topics. The duration of the interviews ranged from 18 min to 1 hr and 24 min with a mean duration of 53 min. Interviews were audiotaped with the participants' informed consent and then transcribed verbatim.

2.4 | Analysis

Data were analysed using IPA. IPA is concerned with the detailed exploration of how people make sense of their personal and social world (Smith & Osborn, 2008). The aim is to explore an individual's

personal perception or account of an event or experience as opposed to an objective description of the object or event itself. IPA is a dynamic process based on the assumption that the researcher has an active role in the research process; the researcher influences the extent to which they access the participant's experience and how they interpret and make sense of that experience.

Data analysis was carried out by the first author and followed the stages set out by Smith et al. (2009). The first stage involved the close reading and rereading of the transcript to become familiar with the interview content. Second, the transcript was read through line by line, noting points of interest and significance on a descriptive, linguistic and conceptual level. Third, the transcript and initial notes were reread, with emergent themes noted. At the fourth stage, themes that were considered as connected were grouped into overarching themes and given a descriptive label, after which these groups of themes were discussed within the research team. As a result, some additional changes were made in the grouping or descriptive labelling of themes. To ensure that the analysis was carried out in a rigorous way and that interpretations made by the first author were of an explicit nature, all stages involved a discussion with a second researcher to provide an audit of the analysis. Also, a reflective journal was kept to map all the decisions that were made. These stages were repeated for each transcript after which the overarching themes for each interview were compared and discussed with the research team to find patterns across cases. As the interviews were carried out in Dutch, the initial analysis was conducted in the same language. Findings were then translated into English for discussion with the international research team. To ensure the meaning of what people talked about was kept during the translation process, the findings and the final paper were discussed with an English native speaker who was fluent in Dutch.

3 | RESULTS

The three overarching themes that emerged were as follows: (A) relationships with staff placed within a personal history, (B) relationships with staff within an organisational context and (C) staff support and interviewees' place in the world.

3.1 | Theme A: Relationships with staff placed within a personal history

Across interviews, it became clear that the nature and meaning of relationships with staff needed to be understood in the context of participants' social histories.

All participants placed a high value on staff being people who were there for them, although this held various meanings for them. Four participants thought that staff "being there for you" meant that they were one of the closest and most significant social relationships they had. The salience of these relationships with staff was juxtaposed with the difficulties the participants had forming close and confiding relationships with people in the wider community. For example, Kenneth, a 27-year-old man who lived in his own apartment in

the community, described the lack of significant relationships in his life, such as family relationships, friendships or an intimate relationship, and talked about his frustrations about this.

So I became friends with myself, just trying to keep myself as a friend. You are born alone and eventually you will die alone as well. That is just how it is. And in the meantime, you have to be lucky to meet someone. I have not been lucky in that way. I have not been that lucky when it comes to love, because I have never had a girlfriend. And that is frustrating, you know. Really, it is the most frustrating thing. (Kenneth)

Kenneth experienced feelings of loneliness and social exclusion and felt that it was vital to have someone there for him, unconditionally. As a result, he wanted to develop close, informal relationships with staff. However, because staff failed to live up to his expectations, he often became frustrated with them, complaining that they had limited time, did not always pay proper attention to him and could be distant and formal in their approach. Kenneth found it particularly hard to cope with the idea of having a distant relationship with young, female staff whom he found attractive.

There are some pretty nice staff members around here, which has always been a pitfall. You see, there are a lot of female staff working at (name of service provider). Some of them are really young and occasionally I have even had a crush on one of the staff members. Then they will say: you should not get a crush on staff members. Yeah, okay, they are talking nonsense. Getting a crush on them can happen, right? That is just normal. (Kenneth)

Consequently, Kenneth disliked being supported by younger female staff, because he felt uncomfortable talking to them about his feelings of loneliness, his need for intimacy and about his problems in general. Instead, he preferred relationships with staff who were older than him and who he could regard as "mother" figures. Kenneth also thought that older and more experienced staff members were wiser and able to give better advice about sensitive topics than younger staff.

Lynn, Daniel and Brian also valued their social contact with staff and informal interactions that were not directly support-related, such as having a chat, drinking coffee, playing videogames and going out together (e.g., going for a drink/dinner or sports game). They particularly enjoyed one-to-one social activities with staff.

It was also nice that I could do something with just my key support worker, doing something together, solely with her. Having dinner and a talk, that is what we did. (...) We went for dinner and a soccer game. Yeah, it's really nice going to do things and then you have more time for each other and you can also have a chat, because you have more time for one another. (Daniel)

Contrary to Kenneth, Brian, Daniel and Lynn's experiences, Thomas and Jill talked about meaningful contact or "being there for you" in a way that was mainly related to practical support. They appreciated being able to talk about their problems and getting information and advice that they needed from staff. For example, Thomas, a 22-year-old man who lived in his own apartment, talked about how staff are always there for him when he does not understand certain information or if he does not know how to deal with something.

They give me good advice and tips, such as "hey, this is the best way to do that". Instead of what I had in mind. And if I have planned something and I want to do it, then I have the feeling that it usually goes wrong. (Thomas)

Interestingly, Thomas highlighted the significance of his family and particularly his mother, when being interviewed about his staff support. He talked about the way staff and his mother discussed important matters. Moreover, he said that he talked to his mother when he was having problems with staff and explained how his mother stood up for him. Thus, he appeared to make sense of his relationship with staff in the context of his relationship with his mother, who lived close-by and had been actively involved in supporting him throughout his life. Furthermore, Thomas talked about the significance of his friends, feeling they are there for him when needed.

It was quite difficult for me to speak about, and my friends understood that and helped me a lot: either they texted or called me. Asked me how I was doing. Yeah, then I think to myself, those are real friends, they just ask you how you are doing. Yeah and that sort of thing. That makes me feel good. (Thomas)

Like Thomas, Jill (a 30-year-old woman with a history of frequently moving of home) talked about her relationship with staff in a way that was mainly support related (i.e., talking about problems, and help with finances). However, her experience with staff was quite different from Thomas'. It seems she had developed a general lack of trust towards staff due to negative past experiences.

In other organizations that was an issue. They treat you like you are some kind of criminal or... that you are less than them, you know what I mean? And...especially that. That you are less than them. And I'm not, nobody is. Everyone is the same. So why would you treat someone like that? (Jill)

As a result of negative past experiences, Jill tended to withdraw from staff and even, on some occasions, to refuse support, despite experiencing a different approach of current staff in which she felt to be treated like an equal.

I've never experienced that before. That they treat you as an equal. It creates trust. It creates trust in the people who work here. For me that is very important. (Jill)

Although Jill talked about having developed more trusting relationships with her current staff, she preferred to have minimal contact with them.

3.2 | Theme B: Relationships with staff within an organizational context

Continuity of support was very important to participants. Brian talked about receiving support from two main staff members, from one of them for more than 9 years, since he had moved in with his current service provider. He felt this continuity had allowed him to build a close personal relationship with his support worker and that she had developed great insight into his support needs.

She has been my key support worker right from the start. So, yeah, that is quite a difference. And through that you build something together. You don't have to agree on everything, but you build something together. (...) You get to know each other, you get to know each other better. She comes to understand me better. That I am emotional at the moment, or glad or happy. She can tell from my face when something is going on. (Brian)

Consequently, Brian said he would only talk to this key worker when he had a problem or felt emotional. However, he reported that the other staff member found it difficult to accept the bond he had developed with his main support worker and tried to force him to talk about personal matters with her as well.

Yeah and my key support worker knows that. She knows me much better. She already had the first piece of paper in her hands, she has been involved from the beginning up till now. So she knows what I am like. And the other [staff member] still tries to see how far she can go. (Brian)

In contrast to Brian, Daniel talked about being supported by a large team of staff with a high turnover. As a result, Daniel seemed to have few personal relationships with staff and often felt rejected by them. Moreover, he thought that staff tended to favour other people with intellectual disability.

And then every time that other clients call she says: "yeah I'm with Daniel at the moment, but I will be with you as soon as possible." Then she asks me if I have anything else that I would like to say. Yes, of course I have, but then she says: "Okay, but I do not have much

time, I really have to move on to the next client." So she is with me for an hour or so, maybe a bit longer. So, then I think: If you have to go, just go. (Daniel)

However, like Brian, Daniel did value the relationship he had with his key worker and the support she provided. He felt she was there for him in a genuine way.

Like Daniel, Kenneth also talked about high staff turnover due to cuts in services. This meant that Kenneth had no say over which staff members would stay or go. His support hours were also cut back, adding to his sense of abandonment. The loss of staff members, with whom he had developed a close bond, was particularly keenly felt.

Unfortunately we are not the ones who get to decide who [which staff members] we would like to keep, that is up to the Board of Directors. And the Board does not always go along with our choice. That sucks. You see, those people in charge of the organisation have no idea what is going on in the workplace. (Kenneth)

Lynn and Thomas talked about how upsetting it was to be supported by a staff member who was unsympathetic.

So, because I hadn't taken my medication I had such a stomach ache. I had to have my medication, otherwise I didn't think I could make it through. Then my roommate pushed the button [call for assistance]. Then she [staff member] came and asked me what I needed. I asked her if I could have my medication and she said: "Can't you just wait?"... drama, drama, drama... and then eventually she gave me my medication. (Lynn)

As Thomas and Lynn both had low levels of self-esteem, these negative interactions with staff were especially troublesome and, as a result, they were particularly affected when staff were judgemental. It seemed that Thomas and Lynn were in quite a vulnerable position, as they were not really able to stand up for themselves when ill-treated by staff. Instead, they seemed dependent on other staff or relatives to call those staff members to account.

Jill's past negative experiences with staff need to be understood in the context of frequent moves to different residential settings, resulting in frequent changes in staff. Jill felt she had never fitted into the health and social care system and had even been homeless for a period, living on the streets.

This has been my first permanent residence in, well, one and a half years. (...) I lived on the streets, and, well, in other institutions and such like, here and there all over the country actually. Yeah, there was never a permanent place for me. (Jill)

Jill felt disappointed with the system and with staff in general. Consequently, she wanted to be able to choose the type of support

she needed and appreciated the fact that her current staff team were respecting her wishes.

3.3 | Theme C: Staff support and interviewees' place in the world

A third theme that emerged from the interviews concerned how the participants viewed their disability and need for support, and the impact this had on their sense of self and wider lives.

Participants talked about their experiences of stigma related to the fact that they receive support. For example, Brian talked about his experience of prejudice and rejection when people found out that he lived in housing with the support of a service provider.

Then they ask me where I live. (...) I live in a house with a roof, supervised independent living. In housing of service provider (name service provider). (...) Then you can hear, you can already see, you can already feel that they are going to deal with you harshly. That they won't look at you anymore, or with a cross face, or ... um, yeah, always something. Well, there is always something bad coming. (Brian)

Kenneth was acutely aware of the negative societal attitudes towards those receiving specialist support:

We are normal people too. But people outside [in the broader society], they don't see that that easily. They just think: oh, they are THAT kind of person. (Kenneth)

Kenneth also felt that his family held prejudicial views. He thought his family regarded all people with intellectual disability, including himself, as having a severe disability and rejected him because of these perceptions.

They [family] have never visited me, they've never cared for me. And if I meet them, they act strangely towards me. Because I live within housing with support of a service provider. They have a weird perception of that. They see the website [of the service provider] and they see that kind of people [people with more severe disabilities]. Then, straight away, they have an image in their head and I think: yeah, hang on, that is not how it works. A variety of people with various backgrounds live in accommodation provided by [name of service provider]. (Kenneth)

In addition, Kenneth felt that living in specialist housing for more than 20 years has been a barrier to forming friendships and close relationships with people in the wider community. This is something he feels powerless to change, adding to his feelings of loneliness and exclusion from society.

Listen, do you know what the problem is with our society? People who have nothing to do with support services. I live here in care and that is something that works for me. When you live in care, in an organization for people with disabilities, then it is harder to become part of a group. Because those people [in the broader society] have their own lives, they grew up together, and then I come along. That is not appreciated. Because they already have a good thing going with their friends and you are not needed. And that sounds harsh. (Kenneth)

Participants talked about their struggles with accepting their disability and, as a consequence, their support needs. For example, Brian expressed contradictory views about his support needs. On the one hand, he said that he accepted his need for support in some areas of his life and that it can be helpful. On the other hand, he talked about the fact that it can sometimes be difficult for him to accept that he cannot manage on his own.

When there really is no other way, I will ask for help. Whether you are able to accept that, that is another thing. But I cannot do the impossible, so then I will ask for help. (Brian)

The way Brian talked about his struggle with receiving and accepting support suggests an ambivalence towards his support needs. Brian spoke with an irritated tone of voice about how he sometimes feels patronized by staff. In these situations, he felt that staff treated him like a child. At other times, he talked about feeling comforted by the reassuring gestures given by staff and acknowledged that he needed and valued the support he received. Brian's ambivalence towards his support needs perhaps suggests an underlying struggle with his identity and the sensitivity with which his support is provided.

A pat on the head. On the one hand I can understand it, they do mean well. And secretly, I do know that it will put me at ease. In one way that is nice but on the other hand I think to myself: I'm not a child of five, seven years old who needs a pat on the head. (Brian)

It was important to Brian that staff let him try to perform tasks as independent as possible. He felt irritated towards staff who did not allow him the chance to be as independent as possible. He thought that some staff were too quick to take over tasks from him and that they should not underestimate the abilities of people with intellectual disability.

Furthermore, the struggle with identity and the acceptance of their disability seemed, to some extent, related to how they felt judged by other people. When Brian talked about being rejected when people found out he lived with support, he said that those experiences made him worry about his disability and related support needs, leading to a sense of difference and not being "one of them."

Because I have a care package where I can rely on care 24 hours a day, even during the night when needed, I sometimes think: why am I the one who has this? Why do I have this? Why did this happen to me? Then I start to question myself. That is going to keep nagging at me. I know the answer, but I can't leave it alone. (Brian)

Kenneth's experience was similar to Brian's, though somewhat different as he said that he had experienced difficulties in accepting his disability in the past, but had now come to terms with it. As stated previously, Kenneth often felt that other people regarded him as different and he also felt excluded and rejected. However, it was noticeable during the interview that Kenneth frequently and firmly stated that he felt just as good as anybody else and focused on the things that he is able to do. Moreover, he asserted that his abilities are equally as important as those of anyone else in society. This appeared to be a way of defending his self-worth in a society where he did not feel accepted for who he is.

Listen, we all live here together in order to have a good life. And one person might be good with his hands while another is good at thinking. You see, we cannot all be the same. That would be something. And I am content. I am not ashamed of what is wrong with me. (Kenneth)

Thomas, Lynn, Daniel and Jill did not speak about struggles with identity or the acceptance of disability and their need for support. Thomas stated that he had got used to the fact that he needed to live with support, because it had been this way since he was a child.

Yeah I have got [professional] support since I was very young, so I have got used to it by now. (Thomas)

It seemed that, in his experience, the need for support just reflected the way his life was, as he talked about how he could not imagine a life without staff support.

3.4 | A life of support, putting the pieces together—Kenneth's story

When presenting the themes separately, a sense of their overall meaning in relation to individual participants' lives can be lost. Hence, this last brief section focuses on Kenneth and how the different themes relate to each other in his particular case, as illustrated in Figure 1.

Kenneth was frustrated by his relationships with staff. These feelings seemed to be related to his experience of stigmatization, exclusion and loneliness. As a result of these experiences, it was vital for him to have someone who was there for him unconditionally and Kenneth wanted to have close, personal relationships

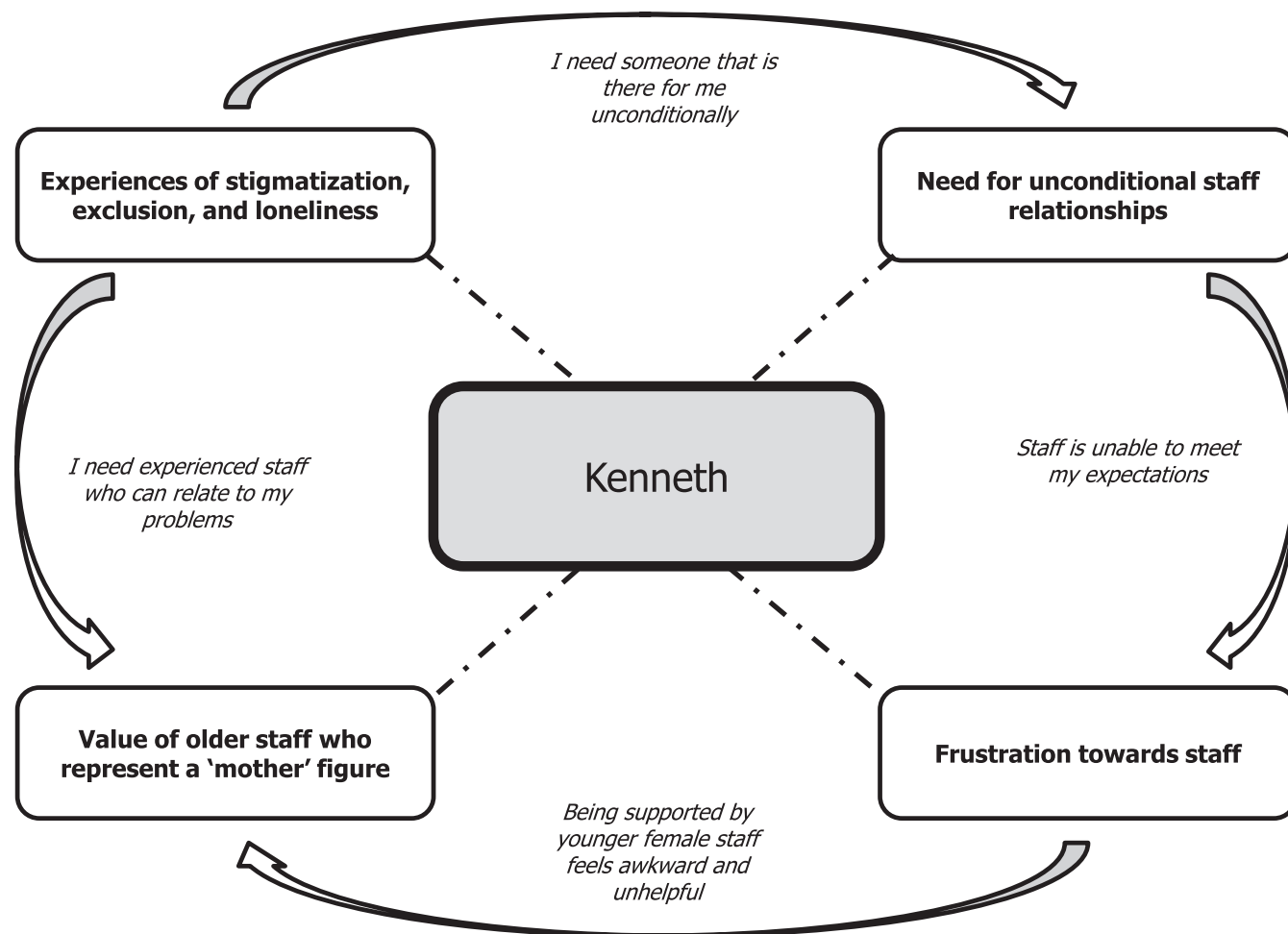


FIGURE 1 Kenneth's story

with staff. However, as staff could be formal in their approach, they failed to live up to his expectations. He disliked being supported by younger female staff, as it felt awkward to talk to them about his problems. Instead, he preferred relationships with staff who were older than him and who Kenneth regarded as "mother" figures. In his experience, they could also relate better to his problems and deal more sensitively with subjects such as intimacy, family and loneliness.

4 | DISCUSSION

This study established an in-depth account of the experiences of six individuals with mild intellectual disability with respect to living with support. Three overarching themes emerged from the analyses: (A) relationships with staff placed within a personal history, (B) relationships with staff within an organisational context and (C) staff support and interviewees' place in the world. First, our findings showed that to truly understand participants' accounts of relationships with staff, these relationships should be interpreted in the broader context of their social histories. Consistent with previous research, we found that relationships with staff were highly valued by individuals

with mild intellectual disability (Van Asselt-Goverts et al., 2013). For the majority of participants, relationships with staff were one of the closest and most significant social relationships they had, with staff not only providing them instrumental support, but also emotional support (Van Asselt-Goverts et al., 2013), and significant and meaningful social contact (Kwekkeboom et al., 2006). In line with previous studies (Bigby, 2008; Mason, Timms, Hayburn, & Watters, 2013; Pockney, 2006), participants described their relationships with staff in a way that included friendship. However, in our study, at least one participant was acutely aware of the fact staff did not meet their expectations for friendships and that "friendships" with staff should not be considered reciprocal. This experience is related to Pockney's (2006) finding that staff and service users often had different perspectives on their shared relationship, as staff seldom considered people with intellectual disability as friends.

The results also showed that relationships with staff played a more central role in the lives of participants when they had few other friendships or close relationships. The informal networks of individuals with intellectual disability are often relatively small (e.g., Forrester-Jones et al., 2006; Lippold & Burns, 2009; Van Asselt-Goverts et al., 2013), also meaning that they may have less access to social capital. Social capital is classically defined as resources

that flow to individuals from their possession of a durable social network, reflecting mutual recognition (Bourdieu, 1986). Access to resources such as emotional and material support, and developing trusted social relationships with others, who are on your side and can help you, are associated with better physical and mental health (Kawachi & Berkman, 2001; Kawachi, Kennedy, & Glass, 1999; McPherson et al., 2014; Riumallo-Herl, Kawachi, & Avendano, 2014). For the current sample, having few friends or social relationships appeared to be linked to feelings of exclusion and loneliness. Research suggests that up to 50% of individuals with intellectual disability are chronically lonely, compared to about 15%–30% in the general population (Gilmore & Cuskelly, 2014). In common with the participants in the current study, other research has shown that individuals with intellectual disability want to have more friendships and/or an intimate relationship (Friedman & Rizzolo, 2018; Healy, McGuire, Evans, & Carley, 2009; Rushbrooke, Murray, & Townsend, 2014). Living in the community had not necessarily led to increased social capital or meaningful inclusion for the participants in the current study. Instead, staff continued to play a vital role in their social lives.

Societal views that stigmatize individuals with intellectual disability may also limit their opportunities for experiencing social and emotional connectedness and, consequently, increase their vulnerability to loneliness (Gilmore & Cuskelly, 2014). Consistent with earlier work on stigma (Ali, Hassiotis, Strydom, & King, 2012), participants were aware of stigma and described experiences of being treated differently or negatively. Stigmatizing views were viewed by participants as a barrier to forming friendships and intimate relationships with people in the wider community; they experienced a gap between “us” and “them” and talked in terms of “we” versus “they” (cf. Goffman, 1963). In line with Goffman’s theory on spoiled identities, stigmatizing views were also related to participants’ struggles with their identities. Paradoxically, the help and support they needed to lead their lives were what some participants felt that marked them out as different and, in their experience, “spoiled” their identity. Partly in response to this experience, Kenneth made efforts to refute or distance himself from perceived prejudice or discrimination (Ali et al., 2012; Beart, Hardy, & Buchan, 2005; Finlay & Lyons, 2000; Jahoda & Markova, 2004). Kenneth used downward social comparison, making it clear that he saw himself as different from people with more severe levels of disability and emphasizing his strengths while minimizing his weaknesses (Ali et al., 2012). Our data suggest that stigma theory has relevance when understanding the lives and identities of people with intellectual disability living in the community.

With respect to societal views, findings suggest that more positive societal views are related to increased social contact with community members (Blundell, Das, Potts, & Scior, 2016; MacMillan, Tarrant, Abraham, & Morris, 2014; Scior, 2011). An important role of staff should be to facilitate meaningful social contact with other people in the community. It has been shown that staff usually prioritize care tasks over social support (McConkey & Collins, 2010), even though it has been shown that staff themselves recognize the

importance of social support for people with intellectual disability living in the community (Van Asselt-Goverts, Embregts, Hendriks, & Frielink, 2014). Staff may prefer to view themselves as facilitators to friendships, instead of fulfilling a friendship role (Pockney, 2006).

Study participants reported that limited staff time, which has become even more pronounced in times of austerity and service cuts, was a barrier to building relationships with staff and also meant that staff had limited opportunity to help promote their social inclusion. The need for sufficient staff time to meet people with intellectual disability’s need for social support has also been highlighted in previous studies (Abbott & McConkey, 2006; Van Asselt-Goverts et al., 2014). Participants also experienced high levels of staff turnover and felt that a lack of continuity was another barrier to building close relationships with staff and may have prevented staff from developing good insight into their support needs. High staff turnover also meant that participants frequently experienced a personal loss of valued relationships. However, maintaining one trusting, longer lasting relationship with a key worker did appear to help some participants deal with staff turnover in their support team.

The results of the current study were consistent with existing research and added to the literature by exploring in detail what individuals with intellectual disability thought and felt with regard to support from staff and, more broadly, their experience of living with support. Our study showed that the experiences of individuals with intellectual disability varied widely when it comes to living with support and their social relationships with, for example, friends and family. Therefore, it is important that support is attuned to the needs of each person. Not all staff have to fulfil the same role for each individual person, as participants displayed preferences for staff members with whom they had developed a trusting or closer relationship. It is important for staff to acknowledge that people with intellectual disability will have preferences for people they get on better with.

There were, however, some limitations of the study. In line with the IPA method, this study focused on the experiences of only six participants and the generalizability of the findings to the wider population of individuals with intellectual disability is unknown. More specifically, our findings concerned individuals receiving 24-hour support in the community in the Netherlands. As support arrangements vary both within and across countries, future research might address support experiences of individuals with intellectual disability in different kinds of support arrangements in various countries to consider possible differences in experiences. Finally, even though we aimed to establish in-depth accounts of participants’ support experiences, Jill’s interview lasted only 18 min (despite the attempts of the interviewer to build rapport before and during the interview). However, the way Jill interacted with the interviewer and the way she spoke in a brief forthright fashion about her support experiences were consistent with her narrative about a lack of trust in staff and a tendency to withdraw herself from them.

ACKNOWLEDGMENT

We would like to thank the individuals who participated in this study and the staff from the service providers who supported recruitment to the research.

CONFLICT OF INTEREST

All authors declare that they have no conflict of interest.

ORCID

Sanne A. H. Giesbers  <http://orcid.org/0000-0001-8358-5806>

Andrew Jahoda  <http://orcid.org/0000-0002-3985-6098>

Petri J. C. M. Embregts  <http://orcid.org/0000-0003-3567-1528>

REFERENCES

- Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of Intellectual Disabilities*, 10(3), 275–287. <https://doi.org/10.1177/1744629506067618>
- Ali, A., Hassiotis, A., Strydom, A., & King, M. (2012). Self stigma in people with intellectual disabilities and courtesy stigma in family carers: A systematic review. *Research in Developmental Disabilities*, 33, 2122–2140. <https://doi.org/10.1016/j.ridd.2012.06.013>
- Arcsott, K., Dagnan, D., & Stenfert Kroese, B. (1998). Consent to psychological research by people with an intellectual disability. *Journal of Applied Research in Intellectual Disabilities*, 11(1), 77–83. <https://doi.org/10.1111/j.1468-3148.1998.tb00035.x>
- Barelds, A., Van de Goor, I., Van Heck, G., & Schols, J. (2010). Quality of care and service trajectories for people with intellectual disabilities: Defining the aspects of quality from the client's perspective. *Scandinavian Journal of Caring Sciences*, 24, 164–174. <https://doi.org/10.1111/j.1471-6712.2009.00701.x>
- Beart, S., Hardy, G., & Buchan, L. (2005). How people with intellectual disabilities view their social identity: A review of the literature. *Journal of Applied Research in Intellectual Disabilities*, 18, 47–56. <https://doi.org/10.1111/j.1468-3148.2004.00218.x>
- Bigby, C. (2008). Known well by no-one: Trends in the informal social networks of middle-aged and older people with intellectual disability five years after moving to the community. *Journal of Intellectual and Developmental Disability*, 33(2), 148–157. <https://doi.org/10.1080/13668250802094141>
- Blundell, R., Das, R., Potts, H., & Scior, K. (2016). The association between contact and intellectual disability literacy, causal attributions and stigma. *Journal of Intellectual Disability Research*, 60(3), 218–227. <https://doi.org/10.1111/jir.12241>
- Bourdieu, P. (1986). The forms of capital. In J. Richardson (Ed.), *Handbook of theory and research in the sociology of education* (pp. 241–568). New York, NY: Greenwood Press.
- Clarkson, R., Murphy, G. H., Coldwell, J. B., & Dawson, D. L. (2009). What characteristics do service users with intellectual disability value in direct support staff within residential forensic services? *Journal of Intellectual and Developmental Disability*, 34, 283–298. <https://doi.org/10.3109/13668250903285630>
- Devi, N. (2014). Supported decision-making and personal autonomy for persons with intellectual disabilities: Article 12 of the UN Convention on the Rights of Persons with Disabilities. *Journal of Law, Medicine, and Ethics*, 41(4), 792–806. <https://doi.org/10.1111/jlme.12090>
- Dodevska, G. A., & Vassos, M. V. (2013). What qualities are valued in residential direct care workers from the perspective of people with an intellectual disability and managers of accommodation services? *Journal of Intellectual Disability Research*, 57(7), 601–615. <https://doi.org/10.1111/j.1365-2788.2012.01565.x>
- Donner, B., Mutter, R., & Scior, K. (2010). Mainstream in-patient mental health care for people with intellectual disabilities: Service user, carer and provider experiences. *Journal of Applied Research in Intellectual Disabilities*, 23, 214–225. <https://doi.org/10.1111/j.1468-3148.2009.00527.x>
- Embregts, P. (2011). *Zien, bewogen worden, in beweging komen [See, be moved, start moving]*. Tilburg, The Netherlands: Tilburg University.
- Finlay, W. M. L., & Lyons, E. (2000). Social categorizations, social comparisons and stigma: Presentations of self in people with learning difficulties. *British Journal of Social Psychology*, 39, 129–146. <https://doi.org/10.1348/014466600164372>
- Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., & Wooff, D. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, 19, 285–295. <https://doi.org/10.1111/j.1468-3148.2006.00263.x>
- Friedman, C., & Rizzolo, M. C. (2018). Friendship, quality of life, and people with intellectual and developmental disabilities. *Journal of Developmental and Physical Disabilities*, 30(1), 39–54. <https://doi.org/10.1007/s10882-017-9576-7>
- Gilmore, L., & Cuskelly, M. (2014). Vulnerability to loneliness in people with intellectual disability: An explanatory model. *Journal of Policy and Practice in Intellectual Disabilities*, 11(3), 192–199. <https://doi.org/10.1111/jppi.12089>
- Goffman, E. (1963). *Notes on the management of a spoiled identity*. Englewood Cliffs, NJ: Prentice Hall.
- Griffith, G. M., Hutchinson, L., & Hastings, R. P. (2013). "I'm not a patient, I'm a person": The experiences of individuals with intellectual disabilities and challenging behavior: A thematic synthesis of qualitative studies. *Clinical Psychology: Science and Practice*, 20, 469–488. <https://doi.org/10.1111/cpsp.12053>
- Hatton, C., Wigham, S., & Craig, J. (2009). Developing measures of job performance for support staff in housing services for people with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 22, 54–64. <https://doi.org/10.1111/j.1468-3148.2008.00439.x>
- Healy, E., McGuire, B. E., Evans, D. S., & Carley, S. N. (2009). Sexuality and personal relationships for people with an intellectual disability. Part I: Service-user perspectives. *Journal of Intellectual Disability Research*, 53(11), 905–912. <https://doi.org/10.1111/j.1365-2788.2009.01203.x>
- Hewitt, A. S., Nord, D., Bogenschutz, M., & Reinke, J. (2013). Community living. *Inclusion*, 1, 17–27. <https://doi.org/10.1352/2326-6988-1.1.017>
- Jahoda, A., & Markova, I. (2004). Coping with social stigma: People with intellectual disabilities moving from institutions and family home. *Journal of Intellectual Disability Research*, 48(8), 719–729. <https://doi.org/10.1111/j.1365-2788.2003.00561.x>
- Kawachi, I., & Berkman, L. F. (2001). Social ties and mental health. *Journal of Urban Health: Bulletin of the New York Academy of Medicine*, 78(3), 458–467. <https://doi.org/10.1093/jurban/78.3.458>
- Kawachi, I., Kennedy, B. P., & Glass, R. (1999). Social capital and self-rated health: A contextual analysis. *American Journal of Public Health*, 89(8), 1187–1193. <https://doi.org/10.2105/AJPH.89.8.1187>
- Kwekkeboom, M. H. (Ed.), De Boer, A. H., Van Campen, C., & Dorrestein, A. E. G. (2006). *Een eigen huis... Ervaringen van mensen met verstandelijke beperkingen of psychiatrische problemen met zelfstandig wonen en deelname aan de samenleving [A house of your own... Experiences of people with intellectual disabilities or psychiatric disorders with independent living and participation in society]*. Den Haag: Sociaal en Cultureel Planbureau.

- Lippold, T., & Burns, J. (2009). Social support and intellectual disabilities: A comparison between social networks of adults with intellectual disability and those with physical disability. *Journal of Intellectual Disability Research*, 53, 463–473. <https://doi.org/10.1111/j.1365-2788.2009.01170.x>
- Longo, S., & Scior, K. (2004). In-patient psychiatric care for individuals with intellectual disabilities: The service users' and carers' perspectives. *Journal of Mental Health*, 13(3), 211–221. <https://doi.org/10.1080/09638230410001669318>
- MacMillan, M., Tarrant, M., Abraham, C., & Morris, C. (2014). The association between children's contact with people with disabilities and their attitudes towards disability: A systematic review. *Developmental Medicine & Child Neurology*, 56(6), 529–546. <https://doi.org/10.1111/dmcn.12326>
- Mason, P., Timms, K., Hayburn, T., & Watters, C. (2013). How do people described as having a learning disability make sense of friendship? *Journal of Applied Research in Intellectual Disabilities*, 26, 108–118. <https://doi.org/10.1111/jar.12001>
- McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. *Journal of Intellectual Disability Research*, 54(8), 691–700. <https://doi.org/10.1111/j.1365-2788.2010.01295.x>
- McDonald, K. E., Kidney, C. A., & Patka, M. (2013). 'You need to let your voice be heard': Research participants' views on research. *Journal of Intellectual Disability Research*, 57(3), 216–225. <https://doi.org/10.1111/j.1365-2788.2011.01527.x>
- McPherson, K. E., Kerr, S., McGee, E., Morgan, A., Cheater, F. M., McLean, J., & Egan, J. (2014). The association between social capital and mental health and behavioural problems in children and adolescents: An integrative systematic review. *BMC Psychology*, 2, 7. <https://doi.org/10.1186/2050-7283-2-7>
- Murphy, G. H., Estien, D., & Clare, I. C. H. (1996). Services for people with mild intellectual disabilities and challenging behaviour: Service-user views. *Journal of Applied Research in Intellectual Disabilities*, 9(3), 256–283. <https://doi.org/10.1111/j.1468-3148.1996.tb00114.x>
- Petner-Arrey, J., & Copeland, S. R. (2014). 'You have to care'. Perceptions of promoting autonomy in support settings for adults with intellectual disability. *British Journal of Learning Disabilities*, 43, 38–48. <https://doi.org/10.1111/bld.12084>
- Pockney, R. (2006). *Friendship or facilitation: People with learning disabilities and their paid carers*. Sociological Research Online, 11(3), Retrieved from <http://www.socresonline.org.uk/11/3/pockney.html>
- Reuzel, E. A. A., Embregts, P. J. C. M., Bosman, A., van Nieuwenhuizen, M., & Jahoda, A. (2017). Perceptions and expectations of regular support meetings between staff and people with an intellectual disability. *Journal of Intellectual and Developmental Disability*, 42(2), 142–150. <https://doi.org/10.3109/13668250.2016.1225951>
- Riumallo-Herl, C. J., Kawachi, I., & Avendano, M. (2014). Social capital, mental health and biomarkers in Chile: Assessing the effects of social capital in a middle-income country. *Social Science & Medicine*, 105, 47–58. <https://doi.org/10.1016/j.socscimed.2013.12.018>
- Robertson, J., Emerson, E., Gregory, N., Hatton, C., Kessissoglou, S., Hallam, A., & Linehan, C. (2001). Social networks of people with mental retardation in residential settings. *Mental Retardation*, 39(3), 201–214. [https://doi.org/10.1352/0047-6765\(2001\)039%3c0201:snopwm%3e2.0.co;2](https://doi.org/10.1352/0047-6765(2001)039%3c0201:snopwm%3e2.0.co;2)
- Roeden, J. M., Maaskant, M. A., & Curfs, L. M. G. (2011). The views of clients with mild intellectual disabilities regarding their working relationships with caregivers. *Journal of Applied Research in Intellectual Disabilities*, 24, 398–406. <https://doi.org/10.1111/j.1468-3148.2010.00622.x>
- Roeleveld, E., Embregts, P., Henriks, L., & Van den Bogaard, K. (2011). *Zie mij als mens! Belangrijke competenties voor begeleiders volgens mensen met een verstandelijke beperking [See me as a person! Important qualities of support staff according to people with an intellectual disability]*. Arnhem, The Netherlands: HAN University Press.
- Rushbrooke, E., Murray, C., & Townsend, S. (2014). The experiences of intimate relationships by people with intellectual disabilities: A qualitative study. *Journal of Applied Research in Intellectual Disabilities*, 27, 531–541. <https://doi.org/10.1111/jar.12091>
- Scior, K. (2011). Public awareness, attitudes and beliefs regarding intellectual disability: A systematic review. *Research in Developmental Disabilities*, 32, 2164–2182. <https://doi.org/10.1016/j.ridd.2011.07.005>
- Smith, J. A. (2004). Reflecting on the development of interpretative phenomenological analysis and its contribution to qualitative research in psychology. *Qualitative Research in Psychology*, 1, 39–54. <https://doi.org/10.1191/1478088704qp004oa>
- Smith, J. A., Flowers, P., & Larkin, M. (2009). *Interpretative phenomenological analysis: Theory, method, and research*. London, UK: Sage Publications.
- Smith, J. A., & Osborn, M. (2008). Interpretative phenomenological analysis. In J. A. Smith (Ed.), *Qualitative psychology: A practical guide to research methods* (pp. 51–80). London, UK: Sage Publications.
- Stenfort Kroese, B., Rose, J., Heer, K., & O'Brien, A. (2013). Mental health services for adults with intellectual disabilities – what do Service users and staff think of them? *Journal of Applied Research in Intellectual Disabilities*, 26, 3–13. <https://doi.org/10.1111/jar.12007>
- United Nations. (2006). *Convention on the rights of persons with disabilities*. May, 2018, Retrieved from <https://www.un.org/development/desa/disabilities/convention-on-the-rights-of-persons-with-disabilities.html>
- Van Asselt-Goverts, A. E., Embregts, P. J. C. M., & Hendriks, A. H. C. (2013). Structural and functional characteristics of the social networks of people with mild intellectual disabilities. *Research in Developmental Disabilities*, 34, 1280–1288. <https://doi.org/10.1016/j.ridd.2013.01.012>
- Van Asselt-Goverts, A. E., Embregts, P. J. C. M., & Hendriks, A. H. C. (2015). Social networks of people with mild intellectual disabilities: Characteristics, satisfaction, wishes and quality of life. *Journal of Intellectual Disability Research*, 59, 450–461. <https://doi.org/10.1111/jir.12143>
- Van Asselt-Goverts, A. E., Embregts, P. J. C. M., Hendriks, A. H. C., & Frielink, N. (2014). Experiences of support staff with expanding and strengthening social networks of people with mild intellectual disabilities. *Journal of Community & Applied Social Psychology*, 24, 111–124. <https://doi.org/10.1002/casp.2156>
- Verdonschot, M. M. L., De Witte, L. P., Reichrat, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: A review of empirical findings. *Journal of Intellectual Disability Research*, 53, 303–318. <https://doi.org/10.1111/j.1365-2788.2008.01144.x>

How to cite this article: Giesbers SAH, Hendriks AHC, Jahoda A, Hastings RP, Embregts PJCM. Living with support: Experiences of people with mild intellectual disability. *J Appl Res Intellect Disabil*. 2019;32:446–456. <https://doi.org/10.1111/jar.12542>